Power to the people: what will bring about the patient centred revolution?
We need to go beyond well meaning policies

Paul Hodgkin chief executive officer¹, Jeremy Taylor chief executive officer²

¹Patient Opinion, Sheffield S3 9EN, UK; ²National Voices, London, UK

The incoming coalition government wasted no time in declaring its intention to “put patients at the heart of the NHS” in England. The 2010 white paper Equity and Excellence: Liberating the NHS promised more choice, control and information. It also promised more shared decision making with “no decision about me without me” and a powerful new “consumer” champion Healthwatch to stand up for our interests. This government has continued a tradition of rhetorical lip service to the centrality of the patient and if anything has ramped up the rhetoric. “Putting patients first,” “patients first and foremost”—the patient friendly platitudes abound in every official document.

What does it all mean? Putting patients at the heart is partly about patients acting as equal and informed partners in decision making, in contrast to traditional medical paternalism. It is partly about patients as consumers of services, empowered through greater choice, better information, and the opportunity to give feedback and rate services. It is also about patients exercising their rights and responsibilities as citizens, as set out in the worthy but little known NHS Constitution. Those who advocate for people with long term conditions increasingly see patients as managers of their own health. Such patients need better information, help, and support to manage. Many patients will say it is about seeing the whole person rather than just the illness—about holistic, joined up care and the importance of compassion, respect, and dignity.

Putting patients first is thus a pick and mix menu from which decision makers can select according to taste. The notion of “patient and public engagement” provides cover for a range of behaviours and attitudes, from the tokenistic to the genuinely liberating. “Patients as consumers” has been a popular item on the menu under this and the previous government. “Patients as victims or potential victims of harm” has sadly become part of the story as a result of high profile failings of care, such as those seen in Mid Stafford NHS Trust and Winterbourne View.

Patients as partners, managers, and citizens—or indeed owners (“the NHS belongs to us all”) says the NHS Constitution)—have had rather less of a look in.

The guidance on participation recently published by NHS England does not entirely transcend the conceptual muddle—for example, how to reconcile “participation” (patients and citizens in the tent) with “insight and feedback” (examining your customer at a distance). Nevertheless, it is an excellent resource, probably the best official articulation to date of putting patients at the heart, and it bears close attention.

The fact that such guidance should be thought necessary speaks volumes about the fraught relationship between healthcare and the citizen. In other areas of life, society demands autonomy and responsibility of its citizens. In healthcare it is different. Perhaps because illness can be inherently disempowering, because the medical model of care continues to dominate, and because the NHS is free at the point of use, behaviours and practices often seem to reinforce the dependency and passivity of the patient.

So what is likely to make a difference in empowering patients in the coming years? We see three trends that could be transformative, all of which come from outside mainstream medicine and which challenge it to a greater or lesser extent.

Firstly, the growing population of people with multiple long term conditions, disabilities, and frailty will demand a different model of care and support—a primarily social not medical model. Such a model should mobilise patients’ own resources and the resources of their families and communities to help them stay well and functioning. It should also integrate the capacity of carers, friends, neighbours, peer supporters, local authorities, the NHS, and the voluntary and community sector. Many of the ingredients for this alternative approach are already in place, and the endless financial squeeze on the public sector could make it irresistible.

Secondly, the slow march towards greater transparency about performance, with national director for patients and information Tim Kelsey as its current lead tub thumper, will continue to shift power from an often secretive and defensive NHS towards citizens.

Thirdly, digital technologies could change everything. It is always instructive to follow the money. In the Connecting for Health decade the English NHS spent around £10bn (€11.9bn; $16bn) on informatics. Meanwhile citizens were also busy
investing in their own informatics—laptops, PCs, smart phones, broadband, and the rest. If we assume a modest spend of £400 a year across each of the 25 million households in the UK on this kit, then citizens spent £100bn over the same decade. While the NHS was in gridlock over what mega-system to buy, citizens were outspending it by an order of magnitude to get everything that Steve Jobs could give them: information, connectivity, mapping, voice, you name it. Coming soon will be personalised genomics from companies like “23andMe,” the ability for patients to upload data—such as blood pressure—on to their medical record, and social media supported behaviour change.

Where will these trends take us? Medicalisation and marketisation could stymie moves to a more social and holistic model of care; transparency exposes inadequacy but does not itself generate the drive to overcome it. The digital revolution could empower or enslave the citizen. It is too early to tell. But two things stand out. Firstly the forces that are driving these shifts are much deeper than health policy. Secondly it is up to us—patients and professionals—to create the future, to make the very best we can of these opportunities.

Competing interests: We have read and understood the BMJ Group policy on declaration of interests and declare the following interests: PH is chief executive officer of Patient Opinion, a not for profit website, where patients, carers, and staff can share stories of care across the NHS. JT is chief executive officer of National Voices, a national coalition of charities in England, which works with decision makers in health and social care to strengthen the voices of patients and citizens.

Provenance and peer review: Commissioned; not externally peer reviewed.


Cite this as: BMJ 2013;347:f6701

© BMJ Publishing Group Ltd 2013